

REFLECTIONS ON AN UNCOMMON JOURNEY: A FOLLOW-UP STUDY OF LIFE MANAGEMENT OF SIX MOTHERS OF CHILDREN WITH DIVERSE DISABILITIES

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This qualitative follow-up study examined life management strategies of parents of children with disabilities, who were originally interviewed in the mid-1990s. The purpose was to determine whether the life management strategies reported in the original study were consistent across almost a decade of time, and whether thematic content of life management strategies shifted across family and child life-cycle stages. Generally, thematic analysis confirmed that parent life management themes held constant across time and circumstances for the six interviewed mothers, with many of the strategies, found to be effective earlier, continuing to prove valuable in effective life management.

Raising a child with a disability introduces multiple stressors that are related to initial diagnosis, ambiguous child prognosis, parental roles and responsibilities, access to and availability of information, resources and services, loss of relationships, and day-to-day unpredictability (Boss & Couden, 2002; Hartshorne, 2002; O'Brien, 2007; Roper & Jackson, 2007; Zaidman-Zait & Jamieson, 2007). In addition, *parents of children with disabilities must raise their children within the context of powerful societal discourse that devalues adults with disabilities and, therefore, holds low expectations for the ultimate 'success' of parenting children with disabilities* (Green, 2007, p. 151). In spite of these stressors, Green (2007) conducted a study of 81 mothers of children with disabilities and found that the hassles of caring for their children did not result in clinically significant emotional distress in the mothers. Similarly, in a study of 55 parents of children with autism, Tway, Connolly, and Novak (2007) found that, despite the demands of parenting their children, parent measures of adaptation and coping were similar to those of parents of typically developing children, suggesting that parents of children with autism tend to be *resilient and highly adaptive* (p. 251). Bernheimer and Weisner (2007) interviewed 102 parents of children with developmental delays and found the number of accommodations parents made as they cared for their children did not relate to greater stress in families. Rather, accommodations were related to *life satisfaction, family well-being, and sustainability of routine* (p. 198).

For professionals working with families of children who have disabilities, research has suggested the need to emphasize strategies parents use to manage life effectively, rather than focusing on possible negative outcomes or overemphasizing subjective caregiving burdens (e.g., Green, 2007; Hartshorne, 2002; Hutton & Caron, 2005; Kearney & Griffin, 2001; Kuhn & Carter, 2006; Tway, et al., 2007). Our research on life management (Scorgie, Wilgosh, & McDonald, 1996, 1997, 1999) utilized qualitative (interview) and quantitative (survey) methodology to study effective life management and affirmations of transformational outcome in three groups of Canadian parents whose children represented a wide range of disability characteristics and age ranges. Our findings indicated that parents used such strategies as trusting their instincts about what was best for their children, valuing what their children contributed to their families and communities, establishing collaborative relationships with professionals, and locating useful information about child-disability and related services. As a result of parenting their children, parents reported such transformations as becoming more compassionate and self-confident, making a difference for others, and gaining a more authentic view of what is valuable and important in life (cf. Scorgie, Wilgosh, &

McDonald, 1998). Two replications of our survey studies in Italy showed that Catholic-Italian parents of children with disabilities utilized similar life management strategies and experienced similar transformational outcomes as for the Canadian parents (Nota, Soresi, Ferrarai, Wilgosh, & Scorgie, 2003; Wilgosh, Nota, Scorgie, & Soresi, 2004). In addition, a study of African-American and Latino-American parents of children with a range of disabilities supported the original findings with regard to transformation and the associated processes (Wilgosh & Scorgie, 2006).

In a recent study of 63 mothers of children with autism, O'Brien (2007) found lower rates of depression in mothers of older children, older mothers, and mothers with higher education, suggesting that across time, parents may become more effective at managing life. According to Sobel and Cowan (2003), most family studies are one-data gathering events, or *frozen sections—slices of families adapting to the impact . . . at a particular moment in their development* (p. 54). Recently, there has been a call for longitudinal research to examine how parents of children with disabilities manage life across time and life stages (e.g., Grant, Ramcharan, & Goward, 2003; Kuhn & Carter, 2006; Sobel & Cowan, 2003). Selzer, Greenberg, Floyd, Pettee, and Hong (2001) used a longitudinal design to compare parents of children with disabilities, parents of typically developing children and parents of children with psychiatric problems. Across 15 years, physical health and psychological well-being outcome measures for parents of children with disabilities were similar to those of parents of typically developing children, though the parents of children with mental and emotional problems reported greater psychological distress. Trute and Hiebert-Murphy (2002) interviewed parent couples of children with disabilities twice, with a twelve-year interval between first and second interviews. Results clearly demonstrated parents' original statements regarding their views of their children, their perceived stress levels, and their psychological well-being remained constant across time. Kearney and Griffin (2001) conducted a series of interviews with six parents, two couples and two single mothers, across an 18-month time span. They reported that parents experienced both joy and sorrow as they raised their children, joy largely associated with child qualities and parent transformation, such as changed perspectives on life, and sorrow associated with pessimistic views of others toward their children. Despite the stresses of parenting, parents reported future family life trajectories that were optimistic and hopeful. According to Kearney and Griffin (2001), parents had . . . *learned to live without expectations, but said they could not function without hopes and dreams* (p. 587).

Finally, Dellve, Samuelsson, Tallborn, Fasth, & Hallberg (2006) conducted a study of the effect of involvement in a five day intensive training program on the stress and wellbeing of 138 Swedish parents of children with rare diseases. Measurements were taken prior to the intervention and at six and twelve month intervals following the training. Baseline measures showed that the majority of parents felt knowledgeable about their child's disability and reported adequate social supports. Fathers' stress related to lack of knowledge and feelings of incompetence. Parents of children who had progressively deteriorating conditions reported the highest physical and emotional stress levels across time. The researchers concluded that the training program was especially helpful in reducing stress in fathers, working mothers and parents of younger children, and that the stress reduction held up across time.

According to Lazarus (2006), the experience of stress alone does not determine outcome; rather, it is how a person copes with and manages stress that determines whether a stressor is ultimately detrimental. It is essential, he concluded, to continue to examine how people cope with and manage situations that are typically considered stressful. The purpose of this study was to conduct a follow-up qualitative study with parent participants from our original qualitative study to determine whether the life management strategies which emerged in the original study were supported across time. We also wanted to determine whether the thematic content of life management strategies shifted as families progressed across family and child life-cycle stages.

Methodology

According to Orbuch (1997), there is a human tendency to seek order and meaning in life events. Following a traumatic experience, people's stories include attributional statements regarding what happened and why (Moule & Streitberger, 1997; Neimeyer, 2002). Therefore, Orbuch maintained, narrative accounts are *better able than standardized survey instruments to represent the rich, complex, interwoven reports [in] populations who are facing major life stressors* (p. 461). Similarly, Lazarus (2006) suggested that coping can best be studied through analyzing *rich in-depth descriptions of the lives of individuals over time* (p. 42).

Narratives embed an event within a personal and cultural framework that provides meaning and directs action (Murray, 2001). In addition, qualitative methodology enables research to capture ambiguous or dialectical responses and emotions that often accompany crisis events (Carroll, Olson, & Buckmiller, 2007).

Approximately eight years following our original qualitative study of life management in 14 Canadian families, nine participant families were located and six mothers agreed to participate in extensive follow-up telephone interviews. At the time of the original study, four of the six mothers were married and two were divorced. At the second data gathering, two of the married participants were still married to the child's father, two were separated, one originally divorced mother had remained single, and the other divorced participant had recently remarried. Four of the mothers were employed full-time, and two, both married, continued to be stay-at-home parents. Of the six children represented in the study (five male and one female), two were diagnosed with autism, two with Down syndrome and two with rare genetic disorders. The age range of the children during the original interviews was 7 – 24 years (mean age = 12) and during the follow-up study was 13 – 32 years (mean age = 20). At the time of the follow-up study, five children still resided with their mother and one lived in a supported independent community setting.

The follow-up interviews utilized the same protocol as the original interviews (i.e., narrative), which focused on effective life management strategies (e.g., *What strategies have been useful to you as you have parented your child?*), parent characteristics (e.g., *What personal characteristics have been important or essential to effective life management?*) and transformational outcome (e.g., *What has your child taught you that you might not have otherwise learned?* and *How have you changed as a result of parenting your child?*). The present data analysis centered on the first question category—life management strategies.

All six follow-up interviews were conducted by the first author, audio recorded and transcribed for analysis. The original themes were used as sensitizing concepts (Bowen, 2006) to guide data analysis. Sensitizing concepts can be utilized in qualitative research to provide a framework for analyzing and organizing data (Charmaz, 2003; Gilgun, 2002). They supply information about what to look for and where (Bowen, 2006). Trustworthiness in the original study was enhanced through member checks, thick descriptions, an audit trail of coding for theme formation, and independent data coders. For the follow-up study, parents were asked to continue the narration of their family's life story, discussing the utility and ongoing application of the original life management strategies. Each participant received a copy of the interview transcription for verification of content. Both the original and the follow-up studies complied with and received university ethical approval.

Findings

The themes which emerged from the original qualitative study are presented in Table 1 (see next page). The focus of the analysis of follow-up data was to compare the original parent themes with effective life management strategies used by parents as their children grew and progressed through life-cycle changes. Data will be presented using the original categories and sub-categories for life management themes 1 - 3.

As parents began their narrative up-date, they spoke of the stresses that had occurred since the original interviews were conducted. Two of the mothers had become separated from their spouses and had begun working full-time. In addition, one of the mothers reported a period of prolonged physical limitation following an automobile injury. Three of the six children experienced serious health problems which resulted in surgery and prolonged hospitalizations. Of those hospitalized, one suffered a near fatal medical emergency and another experienced subsequent brain damage with progressive cognitive deterioration. Another child exhibited increasingly difficult behaviors through adolescence, and, in another family, a younger child had subsequently been diagnosed with disability. Several families experienced deaths of members of their extended family support systems. At least one major stressor was reported by each of the six mothers between the original and follow-up interviews, and four mothers reported multiple major personal, child and family stressors. Nonetheless, five of the six mothers reported that the experience of raising their children had been positive overall and communicated an optimistic future trajectory for both themselves and their children.

Table 1
Summary of themes from original qualitative study of parent life management and transformation

QUESTION 1: What are the strategies parents of children with diverse disabilities use to effectively manage life?

Theme 1: A positive personal reframing of one's thoughts and attitudes about one's circumstances that involves:

- (a) acceptance of the child as he/she is
- (b) a determination to succeed
- (c) discovery of a sense of purpose or meaning in the event
- (d) enhancing feelings of competence and self-confidence
- (e) development of the ability to live successfully with indeterminacy

Theme 2: Maintain a workable balance with respect to personal roles and responsibilities (that is, "who I am" and "what I do").

- (a) Individual (establishing and nurturing physical and emotional health)
- (b) Spouse (value and nurture marriage)
- (c) Parent of child with special needs (balancing roles of parent, teacher, and advocate)
- (d) Parent of other children in the family
- (e) Employee--employer
- (f) Educator of society

Theme 3: Ability to meet personal, child, and family needs by locating and utilizing resources effectively.

- (a) Gathering information
- (b) Collaborating with professionals
- (c) Connecting with other parents or parent support groups
- (d) Utilizing other sources of support

QUESTION 2: Is it possible to identify personal attributes or abilities that characterize parents who manage life effectively?

Theme 4: Personal Characteristics

Theme 5: Decision-making and problem-solving ability

Theme 6: Philosophy of life

QUESTION 3: Is it possible to extract a common theme or themes describing how parents are transformed through their parenting experiences?

Theme 7: Personal transformation (Who I am)

Theme 8: Relational transformation (How I relate to other people)

Theme 9: Perspectival transformation (How I look at life and what is important)

Theme 1: Positive Personal Reframing

Statements of the six mothers in the follow-up study supported original statements in the first theme and sub-themes with some shift in theme content.

Accepting the child as he/she is. Several parents mentioned that, during the early years following their child's diagnosis, they spent a good bit of time trying to find answers and locate appropriate programs and interventions. However, as the years have gone by, they have become more accepting or, as one mother reported, *more at peace*, with the diagnosis, even though they now have a more accurate understanding of their child's overall limitations and the impact on future functioning. A mother of a son with autism remarked, *When you get to the point of complete acceptance, it's not that important to you anymore. You*

move beyond it. Nonetheless, as in the original study, the parents acknowledged that acceptance is crucial to effective family management in all families.

Acceptance was important, parents affirmed, because it enabled them to focus on crafting *quality of life with their child* rather than on trying to cure their child. In addition, acceptance enabled parents to *get beyond the disability* and, as one mother observed, *focus on [my daughter] as a person who has her own life and her own needs, you know, very much apart from me.* As in the original study, valuing what their children contributed to their lives and the lives of others was important to all six mothers. Mothers continued to describe their children with such terms as wonderful, patient, courageous, gentle, insightful, fun loving, teachers, pioneers, and mentors. One mother said of her son, *He has enhanced my life in so many ways, it is hard to be brief about it. He's had so many challenges to overcome and he has handled himself with such courage and such dignity. I have pride in both my children, but with him it's a little bit different.* Parents also shared how teachers, aides, classroom peers, and extended family members' lives have been enriched through their children (e.g., *He had an aide at school last year who said she learned more from him than she could ever teach him, and I think that's really true*). One poignant account shared by the mother of a son who had, himself, experienced serious health problems was the tender way her adult son silently held his grandmother's hand as she passed away in a hospital room. Though he was unable to communicate verbally, the mother reported that her son's presence brought comfort and courage to his grandmother and to others in the room.

One of the six mothers who, in the original interview, stated that she found comfort in the fact that her son, diagnosed with autism, was not *as disabled as other children* referred to him in the follow-up interview as *high maintenance*, with behaviors that were progressively *getting more difficult*. As she compared her own situation with that of parents of typically developing children, she remarked, . . . *sometimes I get bitter. You know, there's deep hurts, I think. It's hard to deal with especially when you see your friends' kids at the same age who are going to university or getting engaged or, you know, they have the empty nest already, and they have the freedom to come and go as they please, and we don't.* Though she later mentioned several positive qualities of her son, these seemed to be situated within the broader struggles she was facing (e.g., . . . *he's got a big heart; for the many bad things he does, he's so sincere, and he does say, 'Sorry, Mom,' and he has a forgiving heart, too*). She described the transition period from high school to community programs as particularly difficult, with parents having to assume greater responsibility for researching and accessing adult program placement.

Determination to succeed. As in the original study, mothers strongly asserted that reaching goals involved parent determination, something that, for each, emerged from their love for and commitment to their children. As one mother commented, *You don't really appreciate it until you're faced with a really critical kind of situation—the depth of your passion. I would fight to the death for my kids and I know that about myself. . . . The fact that you love your child—I think in spite of all of the challenges, you can still have hopes and dreams for them that they can have a life that has meaning. It's not without challenges, but the challenges aren't going to kill you.* Nonetheless, parents affirmed, securing a hopeful future for their children rested largely on their shoulders (e.g., *It's not the system that's going to ensure your child's quality of life*). While parents in the follow-up study were equally determined to secure quality services for their children as they were in the original (e.g., one mother referred to herself as a *mama tiger* in the first interview, and a *pit bull* in the second), the strategies they employed appeared more tempered across time. A mother of a son with multiple needs remarked, *I think I'm much less concerned about the little things. . . . I have learned that sometimes you don't have to do something immediately, that sometimes time takes care of things. . . . And maybe age has something, too, you know. I think that sometimes when you're younger, you are just in 'react' mode all of the time. And I think I'm much more reflective about things.*

Several parents remarked that they believed the choices parents make during early parenting years set a course of action, or a trajectory, for later outcome. One mother who has worked extensively with families commented, *I believe very much that those early experiences as a parent can set you on a course that is very difficult to get off of. What you do in the early years carries through to the later years [positively or negatively].* This was, in fact, true for one of the mothers who, in the original interview, communicated that she was not very assertive and usually accepted what the school suggested (e.g., *I don't think a lot of parents know what's out there anyway, so what's the difference if they tell you all the options. You're baffled by all the choices*). In the follow-up interview this parent continued to describe herself as *passive*,

and blamed her disappointment with her child's high school programming on her lack of assertiveness (e.g., *I probably wasn't assertive enough to go in there and say, 'Look, this is what I want for my son.' Sometimes I feel, um, you just sort of sit back*).

Mothers agreed that, though the job of parenting was *a marathon, not a sprint*, their efforts produced rewards for their children, themselves and others. As one mother reflected, *You will go down a path that you never imagined and that path can be as wonderful as you are able to make it. . . With the lows come the highs, and those highs are incredible experiences*. Parents had learned that taking time to celebrate the *highs* helped to sustain themselves through the rougher patches.

Discovery of a sense of purpose or meaning in the event. In the original study, this theme was strongly connected to the parents' need to answer the *Why?* questions. For many, belief in a purpose or a reason why their child was in their life was important to managing life. In the follow-up study, this sub-theme emphasis did not emerge as strongly. When parents were questioned about whether they still ask *Why?* five answered that they have moved beyond the question (e.g., *I don't ask 'why me?' I see lots of people with problems greater than ours. Now my main question is, 'how do I get through this'*), though two remarked that the child's father had not. While parents in the original study affirmed that one needed to move beyond the *Why?* question to the *How?* question, one mother iterated that both she and her son continue to struggle to find answers (e.g., *I'm still dealing with the 'Why?' Like, just lately, I think, and 'poor me' kind of thing, because it's been so difficult. . . And he starts to weep and cry and asks me, 'Why? . . . Why am I autistic?' And you don't know how to explain to your child*). Grieving, she declared was ultimately *a life-long thing. It's tough*.

Similar to the first study, parents interpreted life events through a personal philosophy or belief system that stayed fairly consistent across time. Two mothers spoke of the importance of agency in responding to life events (e.g., *you are not a victim, though you can choose to act like one*). Another commented, *Sometimes I get frustrated, but I think, well, you know what? Everyone has something to bear. And this is mine and I guess it isn't that big a deal. And I move on*. Another parent simply said, *Sometimes things happen. You just accept what life has to offer and carry on*. In the end, claimed one mother, the only choice one has is *to live the life you are given the best you can* (e.g., *so we go out, we do things, we keep busy, we overcome barriers*). The need to confront the *Why?* questions seemed to abate in parents who managed life effectively; however, parents continued to utilize efficacious attributions regarding the presence of the child in their lives across time.

Enhancing feelings of competence and self-confidence. The majority of the mothers believed that their advocacy efforts, which had begun early in their child's life, had been sustained over the years. While in the original interviews these mothers discussed the importance of learning to trust their own instincts about their children, even at risk of the parents being labelled, as their children aged they have acted from an internalization of this principle (e.g., *I think [over time] you learn how to advocate. You learn how to lobby. You learn how to make change. You learn to have some power and some authority--some ability to influence decisions*). Three of the four mothers whose children were transitioning from high school to adult programming spoke most overtly of their need to once again trust their own instincts about what was best for their children. According to one mother, *Opportunities are as available as you have the energy to pursue. Never accept what is offered to you. Think clearly about what it is you want and then get the support and reach for that*. The fourth mother chose a program placement based on choices made by other parents, even though she had some concerns about the overall quality of the program (e.g., *. . . I was questioning it, but everybody in the community is going there. . .*).

Developing the ability to live successfully with indeterminacy. This theme continued to receive strong support in the follow-up study. Mothers continued to affirm the need to accept that there will be *good days, bad days* and *ugly days*, and not *set themselves up for failure* when plans fall through. As one mother mentioned, *You have to accept that life is unpredictable*. Therefore, they unilaterally supported the importance of parental flexibility and adaptability to effective life management. Two of the single parents shared how they had had to creatively craft modifications to their work situations that enabled them to adapt plans on short notice when necessary. Several spoke of the stress of finding needed respite or on-call

babysitting services for their young adult children when circumstances, such as child or parent illness, required immediate changes of plans.

Across the board, the mothers also spoke of the need to balance living in the present, (e.g., *take one day at a time and enjoy each good moment*), with planning for the future. This was especially true for mothers whose children were at transition points into adulthood. One mother asserted, *When he was younger I remember my mother saying to me, 'Don't worry about the future. You've got enough on your hands now, so deal with what you've got today.' And I did that very well. But now that he's seventeen-and-a-half, I'm starting to think, 'Okay, now what comes next?'* Not knowing what the future will look like was especially stressful for those mothers whose children's prognoses were either uncertain or deteriorating. Limiting their focus to the present, they claimed, was a helpful strategy for life-management. The mother of a child with uncertain prognosis commented, *So at the moment, we're just trying to be in the moment. And, if that's denial, then that's where I'm at.*

Theme 2: Maintain a workable balance with respect to personal roles (who I am) and responsibilities (what I do)

Individual: Nurturing physical and emotional health. As in the original study, mothers spoke of the need to develop strategies to guard their physical and emotional health. These included such activities as exercise, reading, gardening, shopping, sports and getting away—even if just for an afternoon. The essential requirements for participation in self-care or enrichment activities were to emphasize the overall personal benefit achieved and minimize the guilt. As one mother said, *I'm at a point in life where I'd like to be more focused on ensuring that [my child's] needs are met, but also ensuring that I'm having a life as well. That's a big shift for me. Knowing it's okay for me to have my own life.* One of the benefits of nurturing themselves, the mothers claimed, was that they, in the end, had more energy and creativity to bring to their child and his/her needs. Since the initial interview, two mothers had gone back to school and earned advanced degrees. A third returned to work full time. Both stay-at-home mothers spoke of the effect of having their young adult children in the house for longer periods of time following transition from high school. Both mentioned the tension that sometimes resulted from the need to keep their sons active, thus reducing boredom which often produced behavioural escalation, and the necessity of creating private time and space within the home for both their sons and themselves.

Spouse: Value and nurturing marriage. In the original study, four mothers were married and two were divorced. In the follow-up study, only two mothers remained married. Both of these mothers described their marriages as very strong and mutually supportive. It is not surprising, then, that both of these mothers strongly affirmed the need to continue to nurture their marriages (e.g., *we go out of our way to make our relationship a good relationship*). Both of the mothers also maintained that their husbands were their strongest and, in one case, only, source of support.

Three of the four divorced mothers spoke of the difficulty through the years of keeping their children's fathers active in their lives. Two fathers had grown distant from their children, and one continued to remain absent. Part of the tension these mothers had to deal with was guarding their own feelings of resentment over their husbands' *moving on* and leaving them with the responsibility of raising their children, while at the same time understanding and supporting their children's strong desire to connect whenever possible with their fathers.

Parent of child with special needs. Children in the follow-up study were at different life stages than in the original study. Four of the children, all boys, were transitioning from high school to adult services. For that reason, finding vocational and social outlets for their sons was an important focus for each of these mothers. While school transition programs taught some job-related skills, the mothers quickly found that it was, for the most part, up to them to secure vocational and leisure activities for their children, a task that required considerable time and effort. At the time of the interview several children were involved in community volunteer activities, such as recycling and shredding, and assisting at a fitness center, a senior citizen's home, an elementary school, and a pet store. For the most part, the mothers reported that their children were valued on the job and in the community and received positive feedback from people around them (e.g., *He enjoys the time and he feels as if he's contributing*). However, the types of jobs secured as well as the physical and vocational limitations of the child meant that the child had long periods of downtime, which was difficult for both child and parent. One mother remarked, *[My son] was quite lost for awhile because he loved going to school and he needed the routine. Right now, I'm not terribly happy with*

the situation, because if he's not with his worker, he's watching TV. Two mothers, both of sons with autism, expressed anxiety over the effect down-time had on increased involvement in obsessive behaviors. Another difficulty mothers reported as their children transitioned out of high school programs was building social relationships. Several of the children have formed friendships through organizations, such as the Special Olympics. However, mothers who had valued and fought for integrative placements during their child's school years spoke of the difficulties with the social integration of their children into the *adult world*. As one mother said, *Even though [co-workers] like to spend time with him and joke with him, they have difficulty perceiving how they can move from work to friendship—to get a coffee or something.* One mother expressed her frustration that, after years of fighting for her son to be integrated at school, the adult programs offered to him were in predominately segregated environments.

One new concern that had emerged as children progressed through adolescence was the effect of puberty on the children's needs and behaviors. Two mothers shared situations in which inappropriate sexual advances their sons had made toward others had been difficult to deal with socially, mostly because their sons did not comprehend the seriousness of their behaviors. As one mother said, *His body has changed but his cognitive ability hasn't moved too much in ten years.* One mother had to discontinue the services of a capable female in-home care provider due to her son's inappropriate behaviors.

Finally, four of the six mothers spoke of the need to begin thinking of and even planning for long-term living arrangements for their children. Two spoke of future out-of-home placements *four or five years down the line*. Two others, laughingly but seriously, reported that they might be the ones who will eventually move out of their present homes, suggesting that it would be easier for them to make the transition to a new location than their sons (e.g., *He's very clear that this is where he needs to stay. It's a safe and secure base . . . maybe what should happen is I should move out*).

Parent of other children. While, in the initial interviews, many parents struggled with dividing their time between all their children, in the follow-up interviews it was clear that in many cases, siblings were beginning to share caregiving duties with their parents. Several adult children functioned as regular or on-call *child sitters*, providing flexibility for the mother. Two mothers also spoke of the future involvement of an adult child as the primary guardian of his/her sibling. One mother shared that her non-disabled son specifically chose friends who were accepting of his brother (e.g. *If they haven't accepted him, he chooses not to be with them*). A single mother discussed her daughter's future responsibility to eventually care for her brother (e.g., *She knows that's her reality. I know it feels like a big responsibility to her, but she embraces it very much*). Nonetheless, mothers shared the importance of providing respite to their non-disabled children, allowing them time and space for self development. One parent spoke of the decision to send her daughter to another province for university as an opportunity to allow her freedom from the caregiving responsibilities.

Each of the five parents who had more than one child spoke of ways in which their typically developing children had been shaped through being the sibling of a child with a disability. They felt that their children developed such qualities as patience, responsibility, compassion, caring and insight. Three mothers also mentioned that their non-disabled children had chosen careers in healthcare fields, such as medicine, nursing and social work, which, they believed, was a direct result of relating to their sibling.

Employer/Employee: All four of the single mothers, three of whom had children still at home, worked either full or part-time. Each of these mothers felt that work was, in some ways, a cathartic experience that took them beyond a focus on disability. In fact, one mother, as in the first study, stressed the importance of separating her work life from her life with her daughter, as part of her own need for respite. In addition, the three mothers whose children resided at home stressed the importance of flexible scheduling, empathetic employers and colleagues, dependable childcare, and reliable alternate-care options, to maintaining successful employment.

Educator of society. While, in the initial project, this theme received support, in the follow-up study parents did not suggest that it was important for them to educate others about disability. While they were actively involved in finding appropriate services for their children, and certainly were educating service providers and professionals about the unique needs of their children, it no longer seemed incumbent on them to explain their children's disabilities to the public at large. A mother of a boy with autism, shared that when her child was younger, she would volunteer in his classroom and speak to his classmates about autism. However, as he transitioned into high school she felt it was increasingly inappropriate for her to accompany

him into the school or approach his peers. Certainly each of the mothers felt willing to share information about her child when necessary. While most felt that the community at large was more aware and accepting of persons with disabilities, they still longed for a world in which people would demonstrate greater tolerance.

Theme 3: Ability to meet personal, child and family needs by locating and utilizing resources effectively
Gathering information. After their children were initially diagnosed, each of the six mothers spoke of the importance of finding out as much as they could about the child's disability, especially the cause of disability, and locating efficacious services, treatments and interventions. Across time, however, the information important to the parents focused more on understanding and navigating the service *system* than on finding *a diet, a pill, or a cure*. Rather than being seekers of information, three of the mothers were active in disseminating their knowledge and skills to parents of children newly diagnosed. Though several parents mentioned the increase in information available to parents since the time their children were initially diagnosed, the two mothers of children with rare disorders claimed that they probably know *as much as anyone*. Still, they remained attuned to updates in the medical field, still seeking to understand their children's complex syndromes.

Collaborating with professionals. Because the six mothers continued to network with a wide range of professionals, this strategy continued to receive strong support. While in the original study parents focused on developing skills in collaboration, especially with medical and educational personnel, in the follow-up study their focus was more on using those skills to secure ongoing services for their children. Interestingly, the three mothers who voiced mistrust of professionals in the original study continued to experience mistrust of professionals across time. For example, a mother whose child had experienced numerous hospitalizations throughout his life recalled, in both interviews, instances in which she witnessed maltreatment of her son, which caused her to wonder whether persons with disabilities received differential treatment in the medical system. At the same time, five parents mentioned specific medical and educational professionals who had made a profound difference in their child's life in the follow-up interview. Four of the six mothers spoke of stressful experiences they encountered during their child's high school year, including failure of schools to provide promised services, breakdowns in communication between parents and educators, and lack of support for inclusion. Two of the parents described their child's last year in public school as *disappointing*. One mother withdrew her child from the school program during his final year due to a negative incident with a teacher (e.g., *He didn't want to go back for the last couple of days of school, and I didn't force him . . . It was a very difficult ending*). Positive educational experiences included such variables as teachers who supported the child academically by diversifying and modifying expectations and strategies, cross-grade consistency with teacher aides, realistic IEP goals, staff who valued parent knowledge and expertise, and home-school collaboration during lengthy child illness or hospitalizations.

Connecting with other parents or parent support groups. While mentioned as essential to effective life management in the initial study, mothers no longer considered parent group involvement requisite for managing their lives in the follow-up study. The two mothers who had remained actively involved in a parent group did so more to share their expertise with parents of children newly diagnosed than to obtain information or support for themselves. They had, in fact, become leaders, not learners. One mother who had not been involved in a parent group during the first data collection, continued to remain uninvolved at follow-up. However, four of the six mothers continued to find support and encouragement through informal contacts with other parents of children with disabilities (e.g., *. . . there is a comfort level in speaking to another parent that you don't always have with a professional. . . to be with people who experience the same kinds of struggles and feelings is a very bonding thing*).

Utilizing other sources of support. As in the initial study, several parents spoke of the importance of family, friends and community support. Three of the mothers said that their immediate and extended family members were their strongest support base (e.g., *I have an incredibly supportive family . . . and some very close friends. And I think that hasn't changed*). One mother spoke of reduced assistance from her parents across time due to aging, and two parents who had reported little family involvement in the first study continued to report lack of involvement in the follow-up study.

Two mothers continued to receive support (e.g., *shared parenting*) from people with whom they had long-standing relationships in their neighbourhoods. One mother continued to receive strong support from her church community, while another struggled with a congregation that she felt knew her needs but did little to assist (e.g., *people don't understand what it's like to walk in your shoes--they have no idea*). An interesting feature of the sources of support parents utilized was that they have been fairly consistent across the two studies.

In summary, data analysis confirmed that parent life management themes held constant across time for the six mothers. Despite the occurrence of life stresses, mothers who had originally constructed effective strategies for managing their lives and who felt empowered continued to experience hopeful outcomes. One mother voiced her struggle with the challenging aspects of raising her near adult son, including irresolution of the *Why?* questions and feelings of concern regarding her ability to craft a meaningful future for her child. Though four of the parents were at transition points with their children, many of the strategies they had previously found effective for life management were continuing to prove valuable.

Discussion

Many of the strategies mothers found effective for managing life have received support in wider research. For example, according to Roper and Jackson (2007), accepting what cannot be changed is a characteristic of resilient parents. Additionally, Bridgeman (2005) purported that parents' views of their children differ from those of professionals, because parents see beyond the child's disability to affirm the child as a person. Kearney & Griffin (2001) found parents' experiences of joy were centered in such meaning themes as the positive contributions of the child to the lives of others, changed perspectives on life and values, and personal benefits, such as becoming stronger. Parents spoke of their children with *admiration, love and optimism* (p. 586).

Research also provides support for the relationship between parental self-confidence and perceived competence on effective life management. For example, in a study of 170 mothers of children with autism, Kuhn and Carter (2006) found that mothers with high self-efficacy (i.e., competency in their caregiving role) scored higher in agency (i.e., maintaining an active caregiving role) and lower in measures of stress, depression and guilt (i.e., the belief that they were not doing enough for their child). One therapeutic strategy suggested by Hartshorne (2002) was that professionals help parents learn to manage and cope with the uncertainties and unpredictability of day-to-day life when a child has a disability. Furthermore, while comparisons with families who are *worse off* may assist parents in the initial stages of family coping, reliance on external comparisons may be maladaptive across time. A finding that emerged from focus group interviews with 30 mothers in Japan addressed parents' fears of an unknown future, especially as their children transitioned from formal schooling (Kasahara & Turnbull, 2005). The researchers suggested that *professionals empower families by offering concrete future-related information, such as examples and models of other children and families* (p. 259) to help parents plan for their child's transition to adulthood.

Roper and Jackson (2007) reported that diagnosis of disability introduces difficulties within family relationships. Spouses often spend less time together, siblings may have to assume caregiving responsibilities, and parents often have less time for interaction with non-disabled children, all of which may produce parental feelings of guilt. In addition, different styles of coping and the tendency to assess blame internally or externally can become causes of stress between spouses (Hartshorne, 2002). Relationships between siblings may also become strained. In a study of 21 families of children with autism, Hutton and Caron (2005) found 75% of parents reported that their non-disabled children were jealous or resentful of their sibling with autism, though this finding was not strongly supported in either the original or follow-up study.

The importance of gathering information is also supported in the literature (cf. Zaidman-Zait & Jamieson, 2007). According to Dellve et al., (2006), information is necessary for parent empowerment, though Green (2007) cautions that information overload or information received from a variety of professionals that is highly fragmented or contradictory, may lead to parental stress and decreased desire to seek information in the future. Additionally, accessing social support has been linked to positive parent and family outcome in numerous studies (cf. Horton & Wallander, 2001). For example, in a study of parents of children with autism, Twoy et al. (2007) found parents accessed support through other parents (90%), agencies and

community services (80%), close friends (68%), extended family members (58%) and medical personnel (56%). Similarly, Hutton and Caron (2005) found that parents of children with autism reported support from grandparents (60%) and extended family members, such as aunts and uncles (90%). Social support was found to reduce perceived stress and improved quality of life in mothers of children with severe hearing impairment (Hintermair, 2004). In the two parents of children with autism in this study, the parent who reported high family support across both studies demonstrated an optimistic future life-trajectory for herself and her child, while the mother who voiced lack of strong social support was less optimistic as she spoke about the future.

Though the follow-up study was limited by number of participants, the findings suggest important implications. First, further study is warranted to test the suggestion that early experiences set parents on a trajectory for later life management outcomes. If this is so, early child and family intervention services must be prioritized following diagnosis. Mothers in the study also indicated that effective life management was linked to locating information and services, acquiring skills in advocacy, and developing supportive relationships with parents and professionals. Parents also needed encouragement to spend time on self-care activities without guilt, realizing that, as they nurture themselves, they will be able to better care for their families. Parents may also need additional assistance and support as their children transition from a very structured public school schedule into more flexible adult programs. When children are unable to secure conventional vocational employment, parents may need assistance to locate or create opportunities for meaningful activities to fill the down-time. Finally, families, including siblings, may need support as they plan for the long-term future care of a family member with a disability. In that regard, society must act to prevent placing the full burden of long-term future care on siblings and aging parents.

Parents need strategies and accommodations that will provide long-term support (e.g., *[We've] come a long way, but there's still a long way to go*). Parents particularly mentioned the need for dependable long-term respite services, and health care, agency and education professionals that provided multi-year support to them and their children. But, most of all, parents wanted their children to live in communities that welcomed them, respected them, and valued their unique but important contributions. One mother commented in closing, *If we all looked at our lives in the same way he does, we'd be a little bit more open, a little bit more receptive, a little bit more willing to take the time that we need to look after ourselves. And we'd all be a little happier and healthier.*

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